The Australian Arachnoid Cyst Awareness Support Group.

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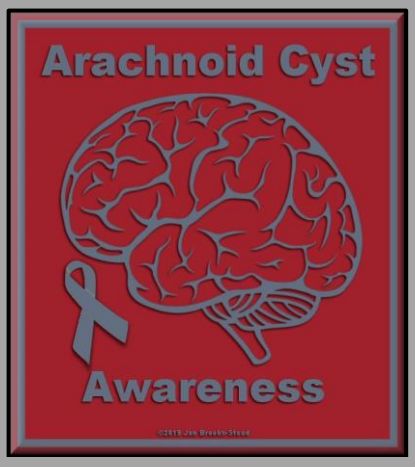

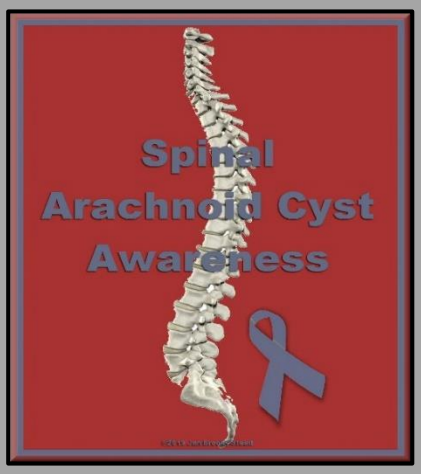

Hello Everyone,

I hope this newsletter finds you all as well as we can all be.

I cannot believe we already have winter here!

I find as I'm getting older the years are going by faster.

In this newsletter I am pleased to finally announce we now have a committee of eighteen members who have come forward to join.

This is wonderful news because now we can go forward and participate in more important events and meetings which will be very important if we are to go forward with

finding help in our medical community and participating in any clinical or research trials.

Thank you to those members who have come forward to be part of our committee.

On Sunday the 24th May we held our first committee meeting over zoom.

The first thing that had to take place at the beginning of the meeting was to vote in our chairperson, our secretary and our treasurer and then committee members who are as follows

Chairperson –

Leonie Axton- Hooper.

Secretary –

Tracey Harrison.

Treasurer –

Amie Baker.

Committee-

Sara Hammmersley

Melissa Sarah

Jay Que

Bonnie Mclean

Marjan Bunning.

We had one late member and four apologies.

The remaining positions will remain open until they are voted in next meeting

Once the voting formalities where over we then went on to discuss funds and fundraising ideas for the future.

This is important because the funds that were being

used for our group have diminished somewhat and I have only had enough from proceeds from sales from the website online store to keep us covered for yearly expenses and office requirements such as printing and postage.

We had plenty of ideas put forward. Those involved with these ideas will look into them ready for next meeting.

In our last newsletter in December, I discussed how I had been taking lots into consideration and deciding if we should become a registered charity or remain a grass roots organisation.

I eventually decided this was the way for our group to remain for a more personal approach to be able to provide support when needed and not be tied to large administrative tasks pulling us away from the time and energy spent being able to engage with our members on a more personal approach.

I had been trying to engage with some of Rare Voice's staff in the office to work out how we can have access to their programs, services and access to grants that may become available.

Unfortunately, due to their time constraints and being so busy I felt I was sent down a rabbit hole trying to navigate their

programs and to be able to access anything I had been interested in looking into for us.

This was when I was told we needed to be a registered charity to be able to have access to Rare Voices material and programs.

I spent a long time researching how to become a registered charity and navigating their booklet on this and their website only to find we didn't have to become a charity.

I then wrote a letter to Nicole Mills the CEO outlining the problems I had navigating the information I had been given and how disappointed I was at finding it so hard to access their programs and any future funding rounds as a grass roots community.

I explained I had written to the health minister in 2023 and I was excited to receive a response outlining how so much funding had been injected into the National Disease Action Plan for Rare Diseases and I was invited to reach out to them.

I did get a response from Nicole Mills; she explained that they had called a meeting to discuss my concerns for improving things for this year 2026 for smaller grass roots organisations.

It is with the formation of our new committee we will need to discuss how

we are to approach our partnership with Rare Voices in the near future.

We hope to have a meeting with them soon to navigate how we are to get the most benefit from partnering with them.

Future Funding for Research Trials

The Accelerated Research Initiative was one of the funding programs within Australia's Medical Research Future Fund. (MRFF) this is was manage by the Australian Governments Dept of Health, Disability and Ageing.

It was designed to help researches with support for developing new treatments, cures and innovative technologies for serious health conditions where there were significant unmet needs.

The goals for the fund where for improving

- patient outcomes

- supporting research into conditions that where difficult to treat.

- encourage innovative approaches to healthcare

-Increasing access to clinical trials and new treatments.

This is a category I feel we with symptomatic Acs fall into.

It has now been merged into The Medical Research Imitative Funds Emerging Priorities and

Consumer Research Entitative under a ten-year plan and is running from 2024-25 through to 2033-34 with approximately $653.6 million allocated over a ten-year period.

I have been researching and this newer intuitive continues to fund research in priority health areas and encourages collaboration between researchers and consumers. (This means patients, carers and community groups.)

If we all make it a priority to fill in our Questionnaire form for our Database because already with those who have filled it in for me, we are beginning to establish long term patient experiences across a lifespan of people with symptomatic Arachnoid Cysts.

Most published Studies follow patients for a short period of time, where as we are able to show outcomes from infancy to patients in their sixties and beyond.

The fact this group has been running for six years now, we are increasing in numbers of patients that show

-Symptoms changing over time rather than remaining the same.

- Ongoing Symptoms such as headaches backpain, fatigue, visual

disturbances and sensory symptoms.

- Bladder and Bowel issues.

- Mobility issues, memory problems.

-The need for repeated surgeries in some patients

- Connective tissue disorders

- In the past and even today, specialists thought a/cs where not genetic, yet we have discovered in many families it is genetic.

-There is autism in many families.

-We have difficulties obtaining recognition that symptoms are related to our cysts.

-Newer neurological symptoms appearing in adulthood.

We definitely fall into a category of unmet clinical needs.

With the help of more patients and families we are able to document

- age at diagnosis

-cyst location and size

-symptoms, surgeries and outcomes.

- long term disability and quality of life impacts.

- employment and education impacts.

- mental health impacts,

- huger impacts on health and disability

From what I have found out many researchers

often ask how many respondents do you have?

The more completed questionnaires we have from Australians affected by symptomatic Arachnoid Cysts, this will carry a lot of weight if we are to consider approaching Australia's Medical Research Fund. MRFF.

The possibility of us reaching this goal will not be far off, but we need every one's help.

The Questionnaire link is at the end of this newsletter.

Changes to the NDIS

Many of us may be concerned with the announcements in the federal Budget regarding the current changes to the NDIS.

I have been reading as much as I can about the changes and pondering the effects to our community.

There will be a roll out of new changes to NDIS access and new services will be provided outside of the scheme.

These new services are called Foundational Supports.

I read that governments are providing 10 billion over the next five years.

This will be split between the Commonwealth and States evenly for this.

These will be for services the NDIS will no longer

cover. I will keep everyone up to date with this as the services are more defined.

One of these services and the most significant impacted changes will be with children from birth to eight years.

Children with developmental delay and or Autism who have low to moderate support needs will be supported through a new initiative called Thriving Kids.

This will involve practical support and help that doesn't need NDIS

requirements.

It will be for Early intervention and Community base supports.

For families with a child on the spectrum and also have an a/c it needs to be understood the many other complexities regarding our symptoms and this condition of symptomatic Arachnoid Cysts.

Therefore, you may have to take into account how this as a whole impacts you and your child and how it impacts their daily lives, before having a preparing for support needs assessment.

Children with a permanent disability or high support needs will remain on the NDIS. To date there has not been an announcement that all current child participants will have a Foundation Assessment and be

transferred onto new NDIS plan.

It is also is unclear what will happen with the children who receive support under Thriving Kids what supports will be in place after the age of eight.

For families like ours where there may be complex conditions, autism, neurological conditions or severe functional impacts (this is how much the condition affects -communication, learning, self-care, self-management and mobility) all associated with a/cs. It is hoped that an accessor will recognise the combined functional impact that multiple conditions that can together create sustainable and ongoing support needs.

The National rollout is to a line with NDIS access changes by 1st of January 2028.

Commonwealth and State services for this change begin by the 1st of October 2026.

It is a concern of different advocacy groups that some children's conditions can grow more apparent as they get older. I will keep everyone up to date.

The other thing is the new rules to access the NDIS and as far as I can understand any future new plans for existing participants. We will no longer need to try to

access medical and other reports to be eligible for the NDIS.

We will be assessed by an assessor and we will have to provide evidence base e.g. of why we are needing supports through the NDIS.

There also will be end dates on plans. Unused funds will no longer roll over.

I will be keeping an eye out for any up dates and will keep everyone informed.

One of our Members Sara Hammersley has been contributing to our newsletters with her research and journey into connective tissue disorders and csf leaks and what can happen.

Sara has been recovering from the surgery she had in late November of last year, so she wasn't able to continue her articles in our last newsletter, but I am very happy that she has found the energy to continue her article in this newsletter!

Thank you so much Sara. I am also learning a lot from your articles.

Hello,
It's been a while since I last wrote, I missed a newsletter or two due to surgical recovery. I hope this is going to be an interesting and informative read. As usual my aim is to inform and create awareness for some of the comorbidities that may coincide with living with an AC and the symptoms

that may become part of our journey.

When we first find out we have an AC we might think we have discovered the reason behind all or some symptoms we are having.

Often, we are born with these cysts and that becomes a clue as to a possible underlying cause of issues that are not immediately apparent and as I wrote in my last article a connective tissue disorder might be one of those reasons.

Another down side to having weak connective tissue is that along with it being weak, stretchy and thin our “dura” and circulatory systems may not behave like they should. This is not only a structural issue but our tissue may tear or deviate fluids which creates a “leak” and this will cause CSF to not flow at optimal pressure. Which in turn creates a situation where not only is there not enough fluid to keep the brain buoyant but the fluid is not cleaning the brain properly and the fluid itself will eventually become murky and sometimes thicker than it should be. The actual brain “cisterns” are not “flushing” properly.

Our Arachnoid layer is a very thin “layer or membrane” ” which is part of the system of fluid production and flow around the brain and spinal cord. It is sandwiched between the “dura mater” and “pia mater” this is where our CSF is continuously

flowing, this precious fluid is so important to the health of our brain and spinal cord.

The CSF flows in the Subarachnoid and it is under debate that when we get an arachnoid cyst as to whether it is actually filled with CSF or not, I have read that, it has been known to be other fluids inside when tested after fenestration.

We can get cysts on our spine as well as our brains but what is obvious is that interruption to CSF flow can have a knock-on effect to the pressure in our brains this can cause at the very least head pain and headaches. We can get high or low pressure or a mix of hyper and hypo CSF pressure.

Getting these things diagnosed is still very difficult and here in Australia we are not great at getting the ball rolling quickly and it usually takes a lot of self-advocating, understanding and "knowledge building" to find a correct diagnosis.

We can get CSF pressure tested through lumbar puncture but results are not always a good indicator of what is going on.

We can sometimes get a CSF leak which can be seen on regular MRI imaging but more often than not we need specialised neuro radiology that is looked at by a good neuro radiologist. These types of images are called myelography they can be

CT or MRI and require different fluids injected into the spinal fluid space to catch “the leak in action” but often they can be hard to pin point.

In Australia we are limited when looking for specialists in this area and it seems Sydney is leading the race but there are some good specialists in Perth and maybe some in Melbourne. The problem is most of the work is done through the private sector but you can go public, as I did, in Sydney, which can take a while. I was lucky to go public (I travelled from Brisbane), through the RPAH and POWH last year for a leak that I have had for a decade or two… unfortunately it lasted for only 5 months and now I am leaking again and this seems to be a common problem when dealing with weak connective tissue. I also have Ehlers Danlos Syndrome.

There are a few different ways to have a spinal leak:

1. A tear in the dura due to a bone spur or the like, creating a hole or even trauma like an accident may cause a tear.

2. A fistula either a venous fistula or less commonly a lymphatic fistula. In these cases, the CSF is leaking out of the nerve root into the blood stream or lymphatic systems.

3. More commonly and easier to detect or treat are the epidural leak injury, when usually a woman is receiving an

epidural and the needle site doesn't heal as quickly as it should and this can create a leak.

"Blood patches" are a way to seal an epidural leak and sometimes used to help detect a fistula leak. This is when blood is injected into the spinal space, with the hope a scab like tissue will form and heal the leak or hold over the leak to pin point an area.

A Venous fistula is more complex this will possibly need a "laminectomy" which removes some bone for access and the nerve root will be clipped, glued or embolised, sometimes there is need for a combination of the 3.

A dural tear is a little bit trickier. Again, some bone will be removed to access the leak and the surgeon will decide on the best way to close the tear using stitching , wrapping or other methods.

Now sometimes these leaks will start as high pressure problems usually when they become chronic. Too much pressure from compression or idiopathic problems or an AC or three (in my case) and you have a perfect storm for weak tissue or an area of weakness that may become "leaky".

High pressure will cause pain that often feels worse when lying down but low pressure or brain sag will feel worse when standing, this is called "orthostatic" head pain. For long time "leakers"

this can vary as the body learns to compensate but it is often a sign that a leek should be considered.

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So along with head pain , neck shoulder and back pain are often present (coat hanger pain), eye sight problems and changes and eye pain, head and face pain / neuralgia, ear pain with no infection, tinnitus, tics, nodding and non-epileptic seizures, the list goes on. On a more serious note these leaks are hazardous on neurological health as well as brain fog and number of cognitive symptoms there is a poorly recognised side of things that is only just starting to get attention, it is becoming known as “spinal dementia”, this can happen after many years of an untreated leak and studies are starting to say if you or a loved one are showing early signs of dementia and seem “too young”, then please consider getting tested for spinal CSF leaks.

These Leaks are not only a spinal problem they can also occur in the cranial subarachnoid space this is often due to a weakness in the tissue and bone especially

around the ear, sinus or skull base and this will need another kind of specialist to diagnose and receive treatment from.

Often the first sign we might have a cranial leak would be apart' from pressure and pain would be a clear liquid dripping from the nose, ear and or eye, usually on one side only, it is clear, thin and "water like" and can have a strange taste or smell. These symptoms can also come with a spinal leak. Sometimes this kind of leak can happen after surgery or spontaneously.

To detect this, you will need to have the fluid tested, you need to catch some, as much as possible, keep it frozen or refrigerated and get it to pathology asap as it is a fluid that gives a lot of negative test results, before you may get a positive…. When leaks are a possibility, you will need a very understanding GP, Neurologist and expert neurosurgeons and a gem of a neuro radiologist.

It can be a tough road and no guarantee of permanent fixes, if your connective tissue is compromised.

I have put some resources below. Your Symptoms with an AC can be debilitating and life changing as we know and we can never know for sure what causes what, but it is important to have an open mind.

If you are ever diagnosed with FND make sure that the "hard ware" (physical structure)

problem, gets attention and not just the "soft wear" (symptoms and cognitive function) before you become at peace with your diagnosis …. we deserve to know what is going on with our bodies. Functional Neurological Disorder does not mean there is no physical cause.

CSF leaks are more common than we realise and not often considered by your average medical professional… Time for more awareness and change….

<u>CFS Leaks Resources</u>

CFS Leakers Downunder – Intercranial Hypotension Patient Support Group

Cranial CSF Leakers this is a USA based support group

Spinal CSF Leak foundation
They have some great resources on U Tube and Facebook, they will keep you up to date with anything new that is happening with research, advocacy and awareness.

……..

I think that's about all we have for this newsletter. We have packed a lot of information into it. I hope this can help many families.

School Holidays are nearly here again, I hope our families with children enjoy their winter holidays and stay safe.

Until next news letter

Warm wishes everyone!

Leonie Axton- Hooper

Founder and Co-ordinator for Arachnoid Cyst Awareness Support Group.

: contribute to publications

: Contribute to our online Arts and Craft Co-Op Hub

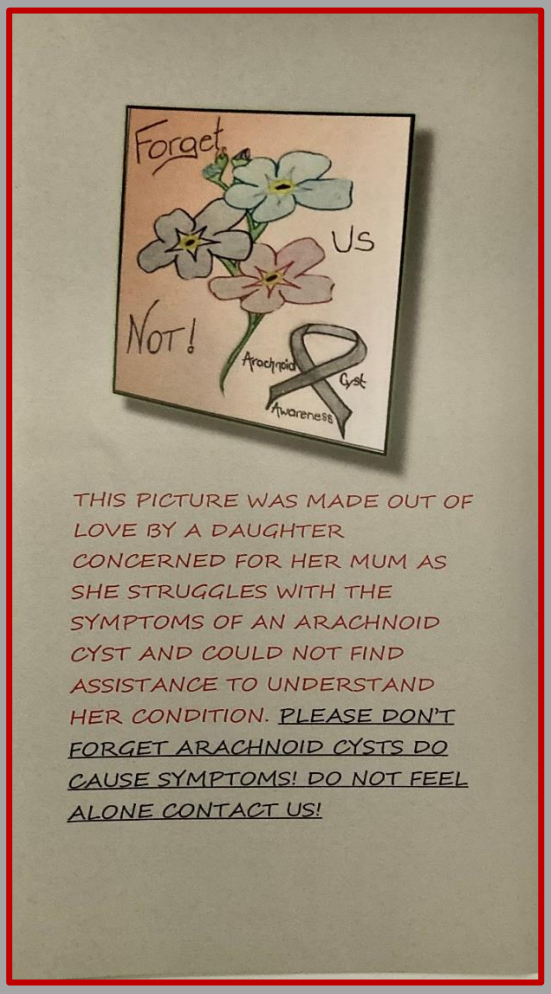
How You Can Help

: Governing, Co - ordinating a Group and

Advocating a Support group in your state.

: Distributing Brochures to Neurology and Neurosurgery rooms, Drs Surgeries and Hospital Neurosurgery wards. Email us for the Brochures.

: Join the Committee'



The Australian Arachnoid Cyst Awareness Questionnaire

Below is an example of the Questions.

Download the questionnaire here -

https://acystawareaust.com.au/wp-content/uploads/2026/06/Arachnoid-Cyst-Awareness-group-Questions.docx

Email to –

acystawaraustralia@gmail.com

You or family members name – You can remain anonymous?

How old are you or your family member?

What state are you from?

At what age were you or your family member diagnosed?

Where is your or family members Arachnoid Cyst situated?

What are the measurements of you or your family members a/c.

Is you or your family member receiving supportive medical treatment?

Are you or your family member being treated or have you been

treated by? Please tick one of the following -

General Practitioner Neurologist Neurosurgeon

Neuro Ophthalmologist

neurophysiologist Pain Management Occupational Therapist

Do you have good support from your family and friends?

Does you or your family member need the use of mobility aids?

Does you or your family member have bowel and bladder issues?

What symptoms do you or family member have?

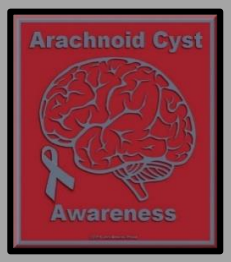
Has you or your family member had surgery?

How many surgeries have you or family member had?

What where these surgeries?

Do you feel you or a family member is declining in health and why?

Thanking for filling in this document, by filling in this document for our database you are helping to create more awareness and a better medical future going forward for all our patients.



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